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ORIGINAL ARTICLE



The impact of an adaptation course on health-related quality of life and functional capacity of patients with inflammatory bowel disease

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ABSTRACT

Background: Inflammatory bowel disease (IBD) has a substantial impact on patients health-related quality of life (HRQoL). In this study, we examined the impact of adaptation courses on HRQoL, psychological well-being, depression and number of sick-leave days of IBD patients.

Methods: The study recruited 142 IBD patients attending an adaptation course of 5–12 days. The courses were specially designed for IBD patients and included multidisciplinary information about IBD, peer support, group activities and encouragement for adequate physical exercise. The participants completed the study questionnaire at the beginning and the end of the course and after six and 12 months of follow-up. HRQoL was assessed with the generic 15-dimensional (15D) tool and depression with Beck's Depression Inventory (BDI). Utilization of health care services and work absenteeism was also assessed. Visual analog scales were used for assessing psychological functioning.

Results: 15D, BDI scores and scores describing psychological well-being were significantly better at the end of the course when compared to baseline (15D 0.82 vs. 0.84, $p < .001$; BDI 11.8 vs. 8.5, $p < .001$). Positive results were maintained during follow up. The percentage of patients receiving peer support rose from 32 to 70% and those with peer support had better HRQoL at the 12-month follow-up ($p = .01$). No significant change in health care utilization or number of sick-leave days was observed.

Conclusion: Adaptation training appears to have a positive impact on the psychological well-being of IBD patients. Peer support appears to be an important factor.

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Adaptation training; health-related quality of life; inflammatory bowel disease; peer support; psychological well-being

Introduction

Health-related quality of life (HRQoL) is a measure of the functional impact of an illness and its therapy on the daily life of an individual, as seen from individual's viewpoint [1]. State of health is one of the most important factors affecting a person's quality of life [2].

Inflammatory bowel disease (IBD) is a chronic condition that often affects young, working-aged individuals. Patients with IBD typically suffer not only from disabling intestinal symptoms such as diarrhea and abdominal pain, but also from extra-intestinal symptoms such as arthralgia and fatigue, which may significantly affect the person's daily life. IBD has a negative impact on patients quality of life, especially if the disease is active [3]. Depression and anxiety are more common among patients with IBD than they are in the general population. The presence of these mood disorders is related to the frequency of disabling symptoms [4]. Increased levels of anxiety, depression and distress have also been observed in patients with inactive IBD [5].

IBD also affects the working capacity of the patients thus causing a burden not only to the patients themselves but also to society [6–8]. Therefore, efforts to improve and maintain the working capacity of patients are vital.

After receiving a diagnosis of a chronic disease, adaptation and coping with the new situation are essential for the well-being of the subject. Coping is defined as an individual's capacity to meet stressful situations, to regulate the emotional distress associated with them and to actively seek ways to alter the unsatisfactory situation [9]. Psychological adaptation after receiving an IBD diagnosis is a complex and dynamic process influenced by many patient- and disease-related factors. After the initial adaptation, many IBD patients face new adjustment challenges because of the chronic and often unpredictable course of the disease [10]. Several ways to facilitate this process have been studied [11–13].

Adaptation courses

As maintaining work ability and the functional capacity of the chronically ill is important both for the affected individuals and society, a number of ways to support the well-being of patients are utilized. One of them is adaptation training courses. In Finland, both the Finnish Social Insurance Institution (SII) and the Finnish patient organization for IBD patients provide outpatient and inpatient adaptation courses for IBD patients with particular emphasis on various group

activities. The purpose of these courses is to reduce the impact of the illness on the patient's working capacity and their mental, physical and social functioning. These courses also aim to increase the self-efficacy of the patients and to enable and encourage the patients to lead as full a life as possible (www.kela.fi). The adaptation courses organized by the SII are statutory and discretionary. There are adaptation courses specially designed for several chronic diseases and conditions. In addition to offering the participants adequate information on the disease and specialist support, peer support is also seen as an important part of the courses along with encouragement towards a healthy lifestyle and adequate physical exercise.

In 2016, the SII channeled 8,380,000 euros (2440 euros/participant) to adaptation courses designed for various conditions. The majority of the patients taking part in the courses were highly satisfied according to feedback questionnaires completed after the course. However, very little is known about the actual impact of the courses on the well-being and working capacity of the participants in the long term. The purpose of this study was to examine the impact of the adaptation courses on the HRQoL, functional and working capacity, and symptoms of depression among patients with IBD.

Materials and methods

Study design and patients

The majority of the study population consisted of participants of inpatient adaptation/rehabilitation courses for IBD patients in the Kaisankoti rehabilitation center in Espoo, Finland during the years 2011 to 2016. The patients were chosen for the courses according to their own application with an attached medical certificate from their doctor indicating the need for an adaptation course and the state of their disease. The adaptation courses designed for IBD patients included a multidisciplinary assessment by a physician, physiotherapist and nutritionist. Assessment by a psychologist and social worker was included, if necessary. The courses were provided by the SII and every course had a maximum of 16 participants, all over 18 of age. The duration of the courses was 10–12 days, divided into two periods separated by 4–6 months. A smaller number of patients was recruited from adaptation courses organized by the Finnish IBD patient organization with financial support of the Funding Centre for Social Welfare and Health Organizations (STEA). These courses were shorter in duration (usually five days in one period). The courses had a very similar program as the longer courses and had a primary goal of offering peer support.

During the courses, the participants were offered information on IBD in the form of lectures and group conversations. Group activities, physical exercise, relaxation exercises, social programs and individual consultations with experts were available. The participants completed the study questionnaire at the beginning and at the end of the course. Follow-up questionnaires were sent by mail six and 12 months after the course.

Study questionnaires

HRQoL was measured with the 15-dimensional (15D), which is a generic, standardized and self-administered measure of HRQoL that yields a 15D profile and a single index score. The 15D is validated and performs at least equally well compared with similar types of generic HRQoL instruments [14, 15]. The 15D has been used in HRQoL studies in various chronic conditions and medical procedures (www.15D-instrument.net), including IBD [16].

The 15D includes the following 15 dimensions: breathing, mental function, speech (communication), vision, mobility, usual activities, vitality, hearing, eating, excretion, sleeping, distress, discomfort and symptoms, sexual activity and depression. Each dimension involves one question with five answer options. The single index score (15D score) can have values between 0 (deceased) to 1 (no problems on any dimension). A difference of ≥ 0.015 in the 15D score is considered clinically important in the sense that a person on average can feel such a difference [17].

The Beck's Depression Inventory (BDI) served as a measure of the level of depression. The BDI is a 21-question inventory that is widely used for measuring the symptoms of depression. Each of the 21 questions has at least four answer options. The answers are scored on a scale value of 0–3 and the total score is the sum of individual scores. The total score can have values from 0–63 with higher scores indicating more severe depression. The scores are rated such that a score of 10 or lower is usually considered as normal and higher scores indicate different levels of mood disturbances and depression. A score of over 40 is rated as extreme depression [18].

Ojanen's scales have been developed to assess the subjective psychological well-being of the respondent. The respondent indicates on a visual analog scale (VAS) the point that best reflects his or her self-estimated view about general life satisfaction, working ability, health, physical condition and amount of exercise. On this scale, zero represents the worst possible and 100 the best possible situation and 50 represents the neutral state [19].

As disease severity and activity are important factors that affect HRQoL and physical function and IBD typically has periods of remission and relapses, the activity of the disease was surveyed by the self-estimated Mayo score for ulcerative colitis [20] and the Harvey-Bradshaw index (HBI) for Crohn's disease (CD) [21]. Both indexes are simple and easy to complete. Additionally, use of health care services and number of sick-leave days were inquired. The patients also had an opportunity to report what was particularly beneficial in the course and how the course could be developed further.

Ethical considerations

The study protocol was approved by the Ethics Committee of the Helsinki and Uusimaa Hospital District (registration number 110/13/03/01/2011) and was performed in accordance with the Declaration of Helsinki. Permission from the SII

was also obtained. All participants provided written informed consent.

Statistical analysis

The data were analyzed by the Statistical Package for Social Sciences, Windows version 22 (IBM SPSS Statistics), with results presented as percentages, means or medians. Differences in categorical variables between groups were tested with the Chi-square test and differences of means with the Mann-Whitney U test or Kruskal-Wallis test depending on the number of the groups tested. Changes in means were examined by t-test. A p value $< .05$ was considered significant.

Results

A total of 195 patients were recruited into the study. Hundred and forty six of them came from the adaptation courses organized by the SII and 49 came from the courses organized by the patient organization. No differences in age, gender, duration of disease or disease activity between these groups were observed. Fifty-three patients did not return the follow-up questionnaires and were omitted from the analysis. Of the remaining 142 patients, six (4.3%) were retired from work and 14 (9.9%) were on sick leave at baseline. The

demographic characteristics of the study population are presented in Table 1.

The mean HRQoL measured with the 15D improved significantly ($p < .001$) during the course and remained at the improved level during follow up. The BDI score also improved significantly ($p < .001$) already during the course period. Most of the patients had BDI scores of ≤ 10 , which is rated as normal. However, at baseline, 4 (2.9%) of the respondents scored > 31 indicating severe or extreme depression. No change was observed after six months. After 12 months of follow up only one respondent scored > 31 . The reported disease activity (as measured by the Mayo score or HBI), was significantly associated with the 15D and BDI scores. During follow up, self-reported disease activity appeared to improve, but only the change in the mean Mayo score was significant ($p < .001$). The significant improvements in the 15D and BDI scores observed during the course were not associated with changes in reported disease activity.

A significant improvement was seen in all of the variables of VAS scales measuring psychological well-being during both the course and follow up. Many of the variables improved significantly already during the course period indicating improved psychological well-being. The scores of the respondents are shown in Table 2.

Table 3 shows the utilization of health care services at different time points and the reported number of sick-leave days. No significant changes in health care utilization were

Table 1. Patient characteristics at baseline.

	All ($n = 142$)	Females ($n = 102$)	Males ($n = 40$)
Mean age, years (range)	43.4 (21–65)	43.4 (21–65)	43.5 (19–68)
Crohn's disease ^a	40 (28%)	33 (32%)	7 (18%)
Ulcerative colitis ^a	95 (67%)	63 (62%)	32 (80%)
Mean disease duration, years (range)	7.9 (1–37)	7.9 (1–32)	8.1 (1–37)
Employed or student	102 (72.3%)	76 (74.5%)	26 (66.7%)
Retired	6 (4.3%)	5 (4.9%)	1 (2.6%)

^aOthers were diagnosed with IBD undefined or microscopic colitis.

Table 2. Characteristics and scores of the patients at baseline and follow-up and p values for the change from baseline.

	Baseline	End of the course	At six month follow up	At 12 month follow up
Smokers (%)	12.1	5.4, $p < .001$	9.1, $p < .001$	11.6, $p < .001$
Peer support (%)	31.7	66.3, $p = .013$	69.9, NS	67.8, $p = .005$
Good knowledge of disease (%)	73.4	97.6, $p = .002$	98.9, $p = .001$	97.8, $p = .017$
Mayo score, mean/median	2.7/3	–	1.3/1, $p < .001$	1.5/1, $p < .001$
Harvey-Bradshaw index, mean/median	4.0/3	–	3.2/2, NS	3.7/3, NS
15D, mean/median	0.816/0.828	0.837/0.850, $p < .001$	0.853/0.867, $p < .001$	0.854/0.864, $p < .001$
BDI points mean/median	11.8/10	8.5/6, $p < .001$	8.9/6, $p < .001$	9.3/7, $p < .001$
Ojanen's scales mean/median				
Life satisfaction	61/65	66/70, $p < .001$	67/70, $p < .001$	68/70, $p < .001$
Working ability	63/65	67/70, $p = .010$	67/75, NS	69/75, $p = .001$
Health	58/60	63/70, $p < .001$	68/70, $p < .001$	66/70, $p < .001$
Physical condition	54/55	58/55, $p = .020$	59/60, $p = .015$	59/60, $p = .004$
Amount of exercise	51/50	56/55, $p < .001$	56/60, $p = .007$	56/60, $p = .005$

Table 3. Utilization of health care services and number of sick-leave days.

	Baseline, mean/median	Six months follow up, mean/median	Twelve months follow up, mean/median
Visits to health center doctor or nurse	2.6/1.0	1.3/0.0	1.3/0.0
Visits to gastroenterologist	0.6/0.0	0.7/0.0	0.5/0.0
Laboratory tests	2.1/2.0	1.8/1.0	1.4/1.0
Radiological examinations	0.2/0.0	0.2/0.0	0.2/0.0
Endoscopies	0.4/0.0	0.2/0.0	0.2/0.0
Sick-leave days (range)	10.7/0.0 (0–93)	7.3/0.0 (0–180)	8.3/0.0 (0–365)

observed. Most of the respondents did not have any sick-leave days due to IBD during follow up. However, of the respondents, 60 (44%) at baseline and 41 (30%) at 12-month follow up reported at least one sick leave day during the past 12 months. While the reported number of sick-leave days was lower after six and 12 months of follow up compared to baseline, the difference was not significant.

At the beginning of the course, only a third reported that they had received previous peer support. This value increased to 66% of respondents during the course; during the follow-up this remained at the same level. Obtaining peer support was reported as the most important benefit of the course by many of the respondents. At the beginning and during the course, peer support was not associated with 15D and BDI scores. However, at the 12 month follow up, those with peer support had significantly better quality of life than those without (15D score 0.866 vs. 0.822, $p = .010$, BDI score 8.2 vs. 11.7, $p = .007$). Only a fifth reported that they had good knowledge of IBD at baseline, but the percentage increased markedly up to 52% during the course. The number of smokers decreased significantly during the course. However, many respondents reported that they resumed smoking during the follow up. Most of the respondents were satisfied with the course. Peer support, lectures and exercise training were in particular reported to be beneficial.

Discussion

IBD is a life-long disease and often affects young, working-aged individuals. While many studies underline the importance of adaptation in IBD patients to maintain their working capacity and quality of life, little is known about how this is achieved [22]. Many educational programs developed for IBD patients have shown no or limited effect on patient psychosocial outcomes [11,12,23]. Disability in IBD is a highly underestimated problem and considerably fewer studies on this topic are available when compared to many other chronic diseases [24].

The impact of inpatient rehabilitation or adaptation courses has been studied in other diseases. However, the arrangements and programs varied markedly between studies. Furthermore, due to the differing natures of the conditions examined, no direct comparisons can be made. For example, while rehabilitation courses were beneficial for patients with cardiac failure and multiple sclerosis [25,26], inpatient rehabilitation did not affect the functional or working capacity of patients with early rheumatoid arthritis [27]. In lung transplant patients, inpatient physical training increased functional capacity but not significantly more than was seen in patients receiving exercise guidance in an outpatient setting [28].

In this study, patients reported improvement in many aspects of psychological well-being during the adaptation course. This was still observed at the 12 month follow up, although this may be due partly to improved disease activity. As IBD is a relapsing and remitting disease, this improvement of disease state may be a coincidence. Another possible

explanation is that after receiving more and adequate knowledge of their disease, the patients were more capable of actively seeking help for their symptoms and had better self-care and coping strategies. Unfortunately, data of any possible changes in the treatment or medications of the patients were not available.

Improvement in BDI scores was also an important finding and reflects the improved well-being of the patients. An earlier study in a US tertiary clinic showed that the presence of a psychiatric disorder may affect the patients perception of their disease and increase the experienced disability [29]. In our study, disease activity, 15D and BDI scores were also highly correlated. Paying attention to depressive symptoms of the patients is important for improving their psychological and general well-being.

Although some of the patients had extensive sick leaves, most of the patients did not report any absenteeism from work during the study period. The number of reported sick-leave days was lower in follow up. However, as the reported disease activity also improved, it is not possible to determine the impact of the adaptation course. A review article revealed that 9 to 19% of IBD patients suffered from short-term absenteeism from work and patients with CD were more disabled than patients with ulcerative colitis [8]. In a Finnish postal study, 25% of IBD patients reported sick-leave days during the past 12 months before the survey [7]. In a Norwegian study, CD in particular seemed to affect working capacity significantly, and patients with CD had twice as many sick-leave days as the general population [6]. Many patients in our survey had problems with their disease, which explains the rather high work absenteeism numbers of many of the patients.

As IBD is a relapsing and remitting disease, it is difficult to differentiate the impact of the adaptation course and changes in disease activity when changes in HRQoL or depression scores, or working ability are examined. This is a weakness of the study. Although disease activity was self-reported (due to the nature of the study), this is an accurate reflection of the patients own perspective of the state of their disease.

The patients in this study may not represent typical IBD patients but they are representative of typical IBD patients attending an adaptation course. In many cases, the idea of participating in an adaptation course arises from the patients themselves. The treating physician may also suggest a course to the patient. The patients participating in adaptation courses may have more concerns about their disease or they may have a more complicated disease course compared to an average patient. This study shows that the situation of these problematic patients often improves in the follow up. No control group of patients not participating an adaptation course could be used as the courses are statutory and all eligible patients were accepted to participate. In this study, some patients participated a shorter course of five days and still reported similar improvement in BDI and 15D scores as the participants of the longer courses. Therefore, in most cases, also a short adaptation course seems to be beneficial for the patients.

Offering peer support has been shown to be beneficial for patients with IBD [30]. At baseline of this study, only a third of participants reported that they had peer support. This increased up to over two-thirds during the course and this rate remained constant in the follow up. A 12 month follow up showed that those with peer support had significantly better quality of life. The possibility for peer support can therefore be considered as one of the most important outcomes of the course.

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Disclosure statement

The authors report no conflict of interest.

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